

Caregiver Support Blueprint *for* Delaware



*A Report to the
Delaware General
Assembly*

May 31, 2015

*This report is submitted to the 147th Delaware General Assembly by the Family Caregiving
Task Force as required by House Concurrent Resolution No. 57.*

Message From The Co-Chairs

The Delaware Family Caregiving Task Force was formed with the passage of House Concurrent Resolution 57 during the 2014 legislative session. The charge of the task force was to make findings and recommendations regarding the support needs of family caregivers who assist older people and people with disabilities. As co-chairs of the task force, we are pleased to present our findings and recommendations in this report.

Nearly half of all Delawareans age 35 and older state they have provided care – either currently or in the past – on an unpaid basis for a loved one. Through our work with the Task Force, we were honored to connect with relatives, partners, friends and neighbors who were willing to provide testimony about their caregiving experiences. We spent many hours listening to their stories, some of which are included in this report. These stories highlighted their dedication and provided us with helpful insight about the support they need to keep going.

Thank you for your acknowledgment of the important work carried out by family caregivers. We appreciate the opportunity to submit this report, which we hope will lead to increased family caregiver support in Delaware.

Lisa Bond

Deputy Director, Delaware Division of Services for Aging and Adults with Physical Disabilities

Jeanne Nutter, Ph.D.

AARP Lead Caregiving Volunteer

Executive Summary

Every day, family caregivers in Delaware assist their parents, neighbors, friends, spouses, and other relatives to enable them to remain at home. About half (45%) of Delawareans age 35 and older are currently providing or have provided unpaid care to an adult loved one who is ill, frail, elderly or has a physical or mental disability.

Family caregivers provide services that would normally take a team to accomplish. They pay bills, shop for and prepare food, offer emotional support, give medications, provide wound care, and maintain the house and yard. Care provided by family and friends is critical to the well-being of their loved ones.

While this unpaid workforce may cost little to the State, their care is not free. The burden on caregivers can lead to decline in physical and mental health, financial stress, and lost productivity in the workplace. Shortages of family caregivers are predicted based on projected changes in the demographic composition of the State. How will we fill this caregiving gap?

In 2014, the Delaware General Assembly passed House Concurrent Resolution No. 57 which established the Family Caregiving Task Force and defined its composition to include representatives from designated organizations in the public, private, and non-profit sectors as well as members from the general public. The resolution directed the Task Force to study the support needs of family caregivers in Delaware and make recommendations based on their findings.

Specifically, the Task Force was charged with carrying out the following activities:

- *Directing the study of policies, resources, and programs available for family caregivers.*
- *Encouraging additional innovative and creative means to support family caregivers to continue to provide needed in-home support for older adults, for distance caregivers, caregivers from special populations, and caregivers in the workplace.*

- *Organizing the taking of testimony on the needs for family caregivers.*
- *Overseeing the process of compiling an inventory of the resources available to family caregivers.*
- *Developing and submitting a report on its findings and recommendations.*

The Family Caregiving Task Force held monthly meetings to accomplish its assigned tasks. Work groups researched policies, resources, technology and innovation related to caregiving. The current Guide to Services for Older Delawareans and Persons with Disabilities was reviewed. In addition, the results of the 2014 AARP Caregiving Survey of opinions and experiences of Delaware residents age 35 and older were made available to the task force members. Finally, six listening sessions were conducted in which, caregivers and/or care recipients were encouraged to share their challenges.

This report is the result of the work of the Family Caregiving Task Force and the testimony given in the listening sessions. The testimony results are found on page 4. The recommendations of the Task Force – which include legislative, budgetary, and policy/program recommendations – are presented on page 8.

The Impact of Family Caregivers in Delaware.

Family caregivers provide an invaluable service to Delawareans. Every day, caregivers help parents, neighbors, friends, spouses, and other relatives remain at home. In fact, over 202,000 family

What Do Family Caregivers Provide?

- *Medication Management*
- *Care Coordination*
- *Bill Paying*
- *Food Preparation*
- *Personal Care*
- *Financial Management*
- *Household Tasks*
- *Transportation*
- *Emotional & Spiritual Support*

caregivers at any given time during the year provide an estimated 132 million hours of care with an estimated value of \$1.56 billion.

According to a 2014 AARP Caregiving Survey of Delaware Residents age 35 and older, 76% want to live independently at home for as long as possible with caregiver assistance when the basic tasks of life become more difficult due to aging or illness.

Family caregivers are relatives, neighbors, and friends who provide unpaid care for loved ones. In the U.S., the “average” caregiver is a 49 year old woman who works and spends nearly 20 hours per week caregiving and has been providing unpaid care for her mother for nearly 5 years.

The vast majority of Delawareans age 35+ strongly support having services that allow people to stay in their own home as they age for as long as possible.

In Delaware, about half (45%) of Delawareans age 35 and older are currently providing or have provided unpaid care to an adult loved one who is ill, frail, elderly or has a physical or mental disability.

More than four out of five of these caregivers are helping or have helped with shopping (86%), household chores (86%) or transportation (82%).

At least seven out of ten are helping or have helped with more complex tasks like medication management (74%) and other nursing and medical tasks (69%).

Why Are Family Caregivers Important?

Family caregivers provide services that would normally take a team to accomplish. On any given day, and often at any given hour, family caregivers perform a variety of roles. They are service providers and coordinators - organizing activities, coordinating care, and providing hands-on support. Many times these activities involve complex sets of instructions or activities, with little to no training or guidance.

Today, family caregivers make up the largest segment of the long-term care workforce in the state and nation. A 2010 national study showed that family caregivers support over 90% of older adults with disabilities who receive long term care in the community.¹ Over two-thirds of these older adults depend on family caregivers for all of their long term care. While this unpaid workforce may cost little to the state in terms of services, their care is not free. The burden on caregivers can lead to poorer physical and mental health, less time for a primary caregiver to socially engage with immediate family and friends, financial stress, and lost productivity in the workplace.

¹ P. Doty (2010). The evolving balance of formal and informal, institutional and non-institutional long-term care for older Americans: A thirty-year perspective. *Public Policy & Aging Report*, 20 (1):3-9.

The impact of caregivers today is the same as it was in the past, yet the scope and dynamics of this care have changed considerably. Caregiving is more complicated, costly, stressful and demanding than at any other time in human history. Increased life expectancy, shifts toward more home and community based services, and the aging of the baby boomer generation have increased the likelihood of an individual becoming a caregiver to family members or friends. The greater complexity of the family caregiving role means that family caregivers are often serving in a wider variety of capacities and performing more substantial care for their loved ones. Also, changing composition of families and households has resulted in more long-distance caregiving and different types of familial caregiving relationships.

Delaware is home to nearly 900,000 people. About half (45%) of Delawareans age 35 and older are currently providing or have provided unpaid care to an adult loved one who is ill, frail, elderly or has a physical or mental disability.

The care and assistance offered by family and friends for their loved ones is critical. Yet, shortages of family caregivers are on the horizon. Rising demand and shrinking familial size are creating a care gap. Over half of family caregivers are the adult children of those receiving care, between the ages of 45-64, and are members of the baby boomer generation. Until now, the numbers of family members in their peak caregiving years (45-64) have kept pace with those needing the most assistance – older adults over age 80. An AARP study showed that currently, there are 7 family caregivers to 1 older adult over 80 needing assistance. But in 2030, that ratio will drop to 4 family caregivers to 1 older adult over 80. In 2050, when 70% of all baby boomers will likely need assistance, the ratio drops further to 3 caregivers to 1 older adult over 80.²

² D. Redfoot, L. Feinberg, A. Houser, *The Aging of the Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers* (Washington, DC: AARP Public Policy Institute, 2013)
http://www.aarp.org/content/dam/aarp/research/public_policy_institute/lrc/2013/baby-boom-and-the-growing-care-gap-insight-AARP-ppi-lrc.pdf

The Demographics in Delaware Are Changing.

The proportion of Delaware's population that is 60 and older is growing more rapidly than other segments of the population. The U.S. Census Bureau estimates that 28.4 percent of Delaware's population will be 60 and older by the year 2030, an increase of 41 percent from 2012. That means there will be about 130,000 more people aged 60+ by 2030.

The population of persons with disabilities in Delaware is also sizable. Currently an estimated 108,397 individuals in Delaware live with disabilities and 92% are aged 18 or over. Among adults with disabilities in Delaware, 66,367 (61%) are under the age of 65 and 42,030 (39%) are aged 65 or older. The incidence of disability, however, increases with age. Whereas approximately 10 percent of younger adults in Delaware have a disability, that rate increases to 32 percent for older Delawareans. For that reason, the number of persons with disabilities in the State is expected to expand with the growth in the older population.

What Caregiver Support Services Are Available in Delaware?

Delaware has an aging and disability network that includes organizations from the public, private and non-profit sectors. Together these agencies have worked to develop service structures that improve the lives of older people, people with disabilities and their caregivers. Caregiver services are those that specifically address the caregiver's needs and may include skills training, education, information and referral, support groups and respite care.

Continued on page 4

What Caregiver Support Services Are Available in Delaware? *Continued from page 3*

In 2010, grant funding from the Administration on Community Living was used to establish the Delaware Aging Disability Resource Center (ADRC). The ADRC was established as a one-stop access point for information and services for older persons and adults with physical disabilities. Since 2010, the ADRC has expanded to provide additional supports across disability groups. Caregivers can access the information by calling the ADRC **(1-800-223-9074)**, sending an email (**DelawareADRC@state.de.us**), using the dedicated website to search for local services (**www.DelawareADRC.com**), or using the **Guide to Services for Older Delawareans and Persons with Disabilities**.

The Division of Services for Aging and Adults with Physical Disabilities (DSAAPD) partners with Newark Senior Center, Wilmington Senior Center, Modern Maturity Center, CHEER Community Center and Easter Seals to run Caregiver Resource Centers located throughout Delaware. The centers are the community's access point for information on a variety of caregiving issues. Staff at the centers can provide information, assistance and support that can be the most helpful in a caregiver's individual situation. They will help caregivers navigate the array of services available, find solutions to individualized concerns and make appropriate referrals. Many Caregiver Resource Centers also have support groups and provide caregiver skills training.

A variety of public funding sources (Medicaid, Older Americans Act, State Funds) are combined to provide direct services that support caregivers. These respite services are designed to provide a break for caregivers. Respite may be provided in the home of the caregiver or care recipient or in another setting such as an adult day or day habilitation center.

In addition, numerous organizations around the state support caregivers by providing specialized information and services to address specific conditions and/or needs. Such organizations include: the Alzheimer's Association of Delaware and Maryland's Eastern Shore; Brain Injury Association of Delaware; Delaware Lifespan Care Network; Mental Health Association of Delaware; United Cerebral Palsy of Delaware; The Delaware Aging Network;

Delmarva Parkinson's Alliance; Family Shade Support and Health Care Alliance of Delaware; and many others.

What Are the Perceptions of Delaware's Caregivers and Their Loved Ones?

During listening sessions conducted across the State, data was collected which revealed common concerns and issues which affect caregivers. It also reinforced the notion that caregiving requires a great deal of time, energy and money. The diverse pool of participants also reflected some cultural differences.

Testimony from caregivers was taken during six listening sessions held from March 2-30, 2015. There was a concerted effort to interview a diverse pool of caregivers, both geographically and ethnically. Of the 46 participants who attended in person 39% were from New Castle County, 37% were from Sussex County, and 24% were from Kent County. The ethnic breakdown was 55% Caucasian, 28% African American, and 17% Latino.

"...Your life totally changes Because it is a 24/7 responsibility. We have been married 51 years. So, I wouldn't change it. I mean this is my husband. The sad thing is that it's not my husband . . . because his personality has changed. They become belligerent, argumentative, and that makes it hard..."

-Caregiver

Most of the caregivers (55%) were taking care of an elderly parent. The next largest group was caring for a spouse (23%), followed by another relative (13%), and an adult child (11%). Three people were caring for young grandchildren.

The age of the care recipients ranged from 10 months to 100 years. The largest percentage was between 70-89 years old (28%). The next largest group was 90-100 years old (15%), followed by the 50-69 year olds (13%). Twenty to 49 year olds made up the smallest group (11%).

The majority of those interviewed (54%) spent 24 hours per week providing care. Those spending 1-6 hours per week made up 22% of the group, followed by those who spent 10-15 hours per week (20%). Only 5% spent 6-10 hours per week.

Of the caregivers, 66% experienced some level of financial stress. Financial responsibilities ranged from paying for groceries and personal items to having almost total financial responsibility for the care recipient.

One caregiver talked about the financial costs of caring for her mother:

"I got behind on car payments; I got behind in a lot of bills. To this day, I'm still—paying. But I am coming out, working two jobs, coming out though, now. But I don't regret what I did for my mother. I don't regret it."

Another caregiver talked about the financial value of providing care, and the way caregivers sacrifice their own financial stability.

"No caregiver that cares for their loved ones should have to worry about, "Okay, how I'm going to pay my car bill? How I'm going to pay my light bill? How I'm going to pay my mortgage or my rent?" We have saved the state thousands, and thousands, and thousands of dollars because we have a heart to care for our loved ones. Now we need someone to care for us, care for the caregiver."

For some families, their income level means they do not qualify for access to paid benefits, yet costs can still be difficult to cover:

"My mother has dementia, severe Alzheimer's tendencies, and the overarching issue is that both of my parents are deaf. So care for them is—has been more difficult, and the access to benefits for them has been limited, because they earn too much money."

Most caregivers relied on some type of assistance. Over half of the caregivers we talked with received professional help, either through state funded programs or by paying out-of-pocket, and 34% relied on family or friends.

Only 17% of those interviewed used respite care and several had poor experience with the service. Surprisingly, 11% had no outside assistance. In some communities, there may be cultural issues related to using outside assistance. **One caregiver explained that they preferred to rely on family and did not consider using paid caregivers:**

"In our culture, we don't think about placing our family member in some Agency—because families, they all should be together..."

Another family member spoke about the difficulty of finding help to prepare meals her Latino family member would enjoy:

"...but we do have home health aides that go in there and do some cleaning. And they're supposed to help me, by cooking food for him. But what happens is, he's Latino and they do not have people that can cook what he likes, so I end up, or my sister or brother's wife end up cooking Latino food."

The majority of the caregivers experienced some type of stress, which impacted their professional lives, family and personal relationships, and health.

"Caregiving impacts not only my work, it impacts my family life, it impacts my personal life, including my professional life. I lose income because I choose to take care of my parents, rather than take a job."

The majority of caregivers worked for companies with no formal policies to support family caregivers. Some caregivers utilized the Family Medical Leave Act (FMLA) – the federal Act that allows many employees up to 12 weeks of unpaid leave to care for family – and others took personal days, vacations days, or sick days to care for their loved ones. Many had to sacrifice and go without pay to care for a family member.

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What Are Your Perceptions of Delaware's Caregivers and Their Loved Ones? *Continued from page 5*

Transportation was a challenge for some caregivers, especially in Sussex County:

"...Paratransit won't come to your house for door to door pick-up if you are ... within a certain distance ... of a designated route, so people can't get to their doctors' appointments. ... So I do all the driving, because he no longer drives. But if for some reason I couldn't drive, we are a half mile off a stop, and he would be expected to make his way to the bus stop."

Despite the diversity of ages, ethnicities, and situations, these caregivers' stories revealed several common challenges. Many reported difficulties balancing the demands of their own jobs and their caregiving duties. Another common problem was the financial strain of caregiving, both from the loss of income from missed work and the money spent on the care recipient. Transportation was also a concern, especially in Sussex County. The data revealed a need for institutions and organizations to be sensitive to the needs of culturally diverse populations.

What Are Communities Doing to Prepare for the Increase in Caregiver Needs?

Around the country, states and communities are seeing the increase in the number of people who need care as an opportunity, rather than a burden. While this changing demographic presents challenges, state and local leaders have forged ahead with exciting new programs and policies to embrace this change. They are promoting aging and disability-friendly communities, increasing funding for needed services, adopting innovative models of service, establishing new supports for the variety of caregiving

roles, changing practices within healthcare to better involve family caregivers and incorporating new technology to make caregiving easier.

At the local level, communities are building on the interests of residents to remain in their homes. One example is the emergence of Villages, mem-

bership networks wherein neighbors help neighbors remain in their homes and communities. This model started in the Beacon Hill area of Boston and has flourished across the nation with the development and establishment of over 200 villages from coast to coast. Delaware presently has two villages: Brandywine Village Network in Wilmington and Greater Lewes Community Village. The structure, management, and activities of these villages differ, but all are tailored to meet the needs of the members in order to help them remain independent at home at an affordable cost.

Over the last few years, several states, including Delaware, have established Caregiving Task Forces to look specifically at the ways the state supports caregivers. Task forces have studied family caregiving and the programs and services available to help people live independently, at home. They have identified existing policies and resources, encouraged new and innovative practices, compiled inventories of resources currently available, and provided recommendations to the legislature and administration on how to improve support for family caregivers in the state. In January 2015, the Mississippi Caregiver Task Force released its report and in November 2015, the New Mexico Caregiving Task Force will finalize its report.

States have also identified individual policies that support family Caregivers, such as workplace flexibility. Additional supports and workplace flexibility can help working caregivers better manage their caregiving responsibilities and their jobs. Both California and Connecticut have passed statewide paid sick days that allow caregivers to take off days to care for a loved one. Paid sick days

"... We have saved the state thousands, and thousands, and thousands of dollars because we have a heart to care for our loved ones. Now we need someone to care for us, care for the caregiver. ..."

-Caregiver

legislation has also passed in cities such as Seattle, San Francisco, Portland, Washington DC, Jersey City, and Newark, NJ. Other states, such as Rhode Island and New York, have instituted family leave insurance programs, wherein a family caregiver can access wage replacement for extended leave and passed laws to expand the Federal Medical Leave Act (FMLA) beyond the federal minimums.

States are also addressing the supports needed for caregivers as their loved ones go into the hospital and transition back home. A 2012 AARP Public Policy Institute study shows that almost half of family caregivers perform medical or nursing tasks for their loved ones. Three out of four caregivers who provide these tasks are managing medications, including intravenous fluids and injections, and most family caregivers report that they received little or no training to perform these tasks.³ In 2014, Oklahoma and New Jersey passed the CARE Act, which puts in place three important provisions: hospitals must record the name of the family caregiver when a loved one is admitted; the family caregiver must be notified if a loved one is going to be discharged to another facility or released to their home; and the hospital must provide in-person instruction about medical tasks that the family caregiver will need to provide at home, such as medication management, injections, wound care and transfers. In 2015, West Virginia, Virginia, New Mexico, and Arkansas passed a version of the bill, and another twenty-four state legislatures are considering it.

*“ . . . People can't get to their doctor's appointments. . .
 . . . I do all the driving, because he no longer drives. . . ”*

-Caregiver

States are finding ways to help resident's better access the health care they need by removing barriers for health care professionals to practice to the full extent of their knowledge and training. As health care needs grow, all of the skills of nurses and direct care workers are essential. Nineteen states give advanced practice registered nurses (APRNs), nurses who have additional training in a specific area, like elder care, full practice authority to provide care to the full extent of their education and training.

Similarly, states are looking at ways to allow nurses to delegate and transfer authority to trained home care professionals who regularly have direct contact with patients. Too often, regulation prevents nurses from having authority to delegate medical/nursing tasks to direct care workers who have training. The 2014 Long Term Scorecard shows ranking of states on nurse delegation.⁴ Together, these changes would prevent the delay of care, which not only hurts consumers, but also places added stress on family caregivers, who all too often are overwhelmed with the rigors of providing and overseeing the care of a loved one.

Families today are spread out geographically and many family caregivers play a critical role in caring and managing assets for their loved ones across state lines. Some family caregivers are legally recognized through a power of attorney or court-appointed guardianship. However, the laws in some states are unclear about the duties of the agent and sometimes third parties, like financial institutions, refuse to honor these legal documents. As such, seventeen states have enacted the Uniform Power of Attorney Act (UPOAA), which, clarifies the duties of the agent, helps to promote autonomy, prevents abuse, and addresses third-party acceptance concerns. Forty states and the District of Columbia have also adopted the Uniform Adult Guardianship and Protective Proceedings Jurisdiction Act (UAGPPJA), which provides uniformity within and across states, reduces jurisdictional conflicts, and helps save time and money for guardians and conservators, allowing them to make important decisions for their loved ones as quickly as possible. These uniform acts function to remove barriers that prevent caregivers from providing for their loved ones, regardless of where they live.

³ Susan Reinhard, et.al., AARP Public Policy Institute *Home Alone: Family Caregivers Providing Complex Chronic Care* http://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/home-alone-family-caregivers-providing-complex-chronic-care-rev-AARP-ppi-health.pdf

⁴ Susan C. Reinhard, Enid Kassner, Ari Houser, Kathleen Ujvari, Robert Mollica, and Leslie Hendrickson, "Raising Expectations: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers, 2nd edition," Commonwealth Fund, Scan Foundation, and AARP Public Policy Institute (June 2014), <http://www.longtermscorecard.org>

Recommendations for Improving Family Caregiver Support in Delaware

The following recommendations are respectfully submitted to the Delaware Legislature for consideration and action:

Legislative Recommendations

1. Legislate standards (similar to the CARE ACT in other states) to involve caregivers in the discharge of their loved one from the hospital to home including:
 - *Recording the name of the family caregiver when a loved one is admitted*
 - *Notifying the caregiver if a loved one is going to be discharged to another facility or released to their home*
 - *Providing in-person instruction about medical tasks that the caregiver will need to provide at home, such as medication management, injections, wound care and transfers (for example, movement from bed to wheelchair)*
2. Enact legislation that prohibits discrimination against caregivers in the workplace
3. Establish tax credits for qualified caregiving expenses and/or making family caregivers eligible to receive payments for some of their caregiving hours.
4. Move the state beyond the minimum requirements of the Family and Medical Leave Act (FMLA), such as covering workers in businesses with fewer than 50 employees, expanding the definition of “family member” to include in-laws and others, expanding the allowable uses of FMLA to include employees taking family members to medical appointments, decreasing the time an employee must work before they become eligible, increasing the length of allowable leave beyond 12 weeks, and including provisions for paid leave.
5. Amend the Nurse Practice Act to allow nurses to delegate additional home care tasks (e.g., medication administration, blood sugar testing, or wound care) to trained direct care workers such as home health aides.
6. Enact, in whole or in part, the Uniform Power of Attorney Act, which would include stronger provisions to prevent elder financial abuse.

Budgetary Recommendations*

1. Provide funding for the development and implementation of a marketing and communication strategy to raise awareness and increase access to existing programs and services for caregivers.
2. Expand funding to ensure that direct care workers such as home health aides are paid competitive wages and have opportunities for career advancement.
3. Make funding available for innovative technologies that make it possible for people to live independently for longer periods of time such as biometric monitoring, fall detection systems, sensor technology and GPS systems.
4. Fund requests across departments which expand or improve the state’s transportation infrastructure.

**Budgetary recommendations could be accomplished through the allocation of new funds or the repurposing of existing funds.*

Policy/Program Recommendations

1. Collaborate with business leaders, service providers, and consumers to explore new policies which support employed caregivers, such as providing paid or unpaid leave, and providing workplace assistance programs for caregivers.
2. Support the implementation of the Delaware Telehealth Roundtable Strategic Action Plan
3. Extend and expand the authority of the Family Caregiving Task Force to monitor implementation of the adopted recommendations and provide ongoing analysis of best practices in support of Delaware’s family caregivers.
4. Review the design and delivery of caregiver services, with a goal of promoting quality outcomes for caregivers, including:
 - *Respite services across the lifespan and to persons of all levels and types of disability*
 - *Cultural competence (accessibility, language, dietary preferences) that honors family choice and direction*
 - *Emergency and drop-in respite*

- *Innovative approaches to decreasing caregiver stress and anxiety*
 - *Skill-building educational opportunities for caregivers on direct caregiving, coordinating multiple services among multiple providers, difficult decision-making, and self-care*
5. Create a comprehensive guide to caregiving for Delaware's caregivers similar to publications created in other states (United Way Caregivers Coalition Pathways for Caregivers, Northern New Jersey)
 6. Keep Delaware's Congressional Delegation informed about the impact of federal funding cuts for durable medical equipment on the state's caregivers.

Task Force Membership

The following organizations participated in preparing this report:

AARP Delaware

Alzheimer's Association Delaware Valley Chapter

Brandywine Village Network of Jewish Family Services of Delaware

Center for Disabilities Studies of the University of Delaware

Delaware Aging Network

Delaware Association of Home and Community Care

Delaware Association of Rehabilitation Facilities

Delaware Division of Services for Aging and Adults with Physical Disabilities

Delaware Healthcare Association

Delaware House of Representatives

Delaware State Chamber of Commerce

Delaware State Senate, Bethany Hall-Long

Developmental Disabilities Council

Easter Seals Delaware

State Council for Persons with Disabilities

United Way of Delaware

Community Members: Ana Figueras, Ken Bock, Yvonne Gordon, Nancy Kinsella and Lawondale Parker

Addendum

The following resources were compiled by the Family Caregiving Task Force's Innovation Committee for inclusion in this report.

Emotional Wellbeing of Caregiver

Individuals are rarely prepared to serve as long term family caregivers. Caregivers may begin in the early stages of a chronic disease or dementia but soon come to realize that this is a long term commitment affecting every aspect of their life. Caregivers can access training materials to guide and better care for their loved one and to help create a safe environment at home. Caregivers will also use technology to stay connected via teleconference support groups, receive needed resources through online coaching tools and stay connected to other family caregivers via digital portals to coordinate care.

Caregiver Education

- **Family Caregiver University:**

http://www.caregiverresource.net/uploads/files/articles/Family_Caregiver_University_2015_Class_Schedule.pdf

- **This Caring Home:** <http://www.thiscaringhome.org/index.aspx>

Resources for caregivers; reviews of a variety of technologies that may assist caregivers

- **Caregiver Coaches:** <http://www.mayo.edu/center-for-innovation/projects/caregivers>

This unique wellness-coaching model integrates a formula to understand key steps to support caregivers and move them toward improved health and wellness.

Coordinating Care

- **Connect Caregiver:** <http://www.ciconnect.com/>

Digital portal to coordinate care – multiple caregivers have access to medications, schedule, measurements, contacts, and more and can interface with one another to coordinate assistance for loved one

- **Unfrazzle:** App to record daily activities and appointments of loved one; can be shared among family/caregivers. Also track personal

- **Lotsahelpinghands:** <http://www.lotsahelpinghands.com/>

Coordinate a care schedule online; multiple users

Enrichment and Activity Resources

- **SAIDO:** <http://elizajennings.org/saido/>

The SAIDO method involves a caregiver (called a “Supporter”) trained to work with two older adults (called “Learners”) by engaging them in simple arithmetic, writing and reading exercises for 30 minutes. In every case, Eliza Jennings residents participating in SAIDO have shown marked improvement. They are much more engaged in daily activities, they eat better, are more socially engaged with caregivers, family and friends, and are generally more optimistic about life and daily living.

Classes offered to provide education and support to caregivers. \$5 suggested donation per class.

- **Art in the Moment:** <http://artinthemoment.org/>

By viewing and discussing well-known pieces of art followed by related hands-on, art making activity, older adults with cognitive disabilities, their caregivers and friends can actively participate together in a mutually fulfilling experience. Art in the Moment will use observing, discussion, and making art as an alternative way for people to communicate, reminisce, and reflect on their life experiences while enjoying themselves in the present moment

Support and Coaching

- **Teleconference Support Groups**

- **Pro-bono Counseling Project:** www.probonocounseling.org

Addendum

Assistance with Daily Tasks/Medical Needs

Maintaining/Monitoring the physical health of the person who requires care is of concern to the caregiver. The concern is heightened when the person has chronic conditions that require oversight to prevent admission to the hospital. Chronic conditions such as congestive heart failure, Chronic Obstructive Pulmonary Disease and Diabetes require careful management. Effective use of technology can decrease the caregiver burden. Technology continues to evolve and is becoming more widespread.

- **Medication Management** - Products are in the market place to assist with the monitoring of medication adherence. Phillips Health (one example) has a product that is able to alert the patient of the need to take a dose of medication and will alert a central station when a dose is not taken. This is accomplished by a caregiver filling medication boxes and setting a schedule for when a medication minder is alerted. If the patient fails to open a box, an alert is triggered to a central station that can call the patient to determine what the status of the patient is. Medication misuse is often will cause a chronic condition to exacerbate.
- **Connecting To Doctors** - (universal patient portal - DHIN <http://www.dhin.org/>)- the use of patient portals can assist caregivers to communicate with medical providers. The evolution of a universal patient portal through DHIN would be instrumental to connect the caregiver to a variety of providers. This would decrease caregiver burden by assisting with care coordination.
- **Biometric Monitoring** - Health monitoring and maintenance is critical for patients who have chronic conditions. Technology can support the patient in self- management. There are numerous systems that can monitor the biometric status of patients. Weight, blood pressure, pulse, oxygen level as well as blood sugar are typical areas of monitoring. Many of the monitoring systems connect to a central station and deviations/alert parameters create an escalation process through established monitoring settings. Tele monitoring is utilized by some home care agencies, health systems, insurance providers as well as the Veterans Administration. Monitoring can be initiated in a variety of ways. There are monitoring systems that prompt the patient to test via a monitor placed in the home. Results are sent through either telecommunications or cellular data methods. Other options include interactive voice response systems as well as web based computer entry. However monitoring occurs, the ability to change the medical regime or educate the patient is an important component. The caregiver has an important role in the development of an effective monitoring strategy.
- **Sensor Technology** - The role of sensors is emerging in home use. Sensors can monitor the patterns of activity for a person. Changes in patterns such as decreased activity, change in “flushing” of a toilet, change in the number of times food is accessed from a refrigerator for example can be early warning systems for health changes.
- **Communication with Doctors** - Language barriers may exist between some caregivers and their doctors; in these instances interpreter services are key. New technologies allow an interpreter to be available via a telephone call on speaker phone, making communication clearer and more effective. <http://www.interpreters-on-call.com/>
- **Innovative products for seniors and caregivers:** <http://www.firststreetonline.com/>
- **Delaware Assistive Technology Initiative:** <http://www.dati.org/>
- **Assistive Technology Resource Center:** At each ATRC, an experienced AT provider is available to discuss personal needs and options. With the demo/loan program, Delawareans can see demonstrations or various AT options or “test-drive” hundreds of AT devices: <http://www.dati.org/aboutus/NewCastleSite.html>
- **CareZone:** App to assist with organizing health information <https://carezone.com/home>
- **Life360:** App to track a person’s location and notify family of arrival at designated location.
- **It’s Never 2 Late:** Computers specifically designed for seniors <http://www.in2l.com>

Addendum

In-Home Monitoring & Technology for the Home

Continued advances in technology will make it possible for caregivers to leave the home and ensure their loved one is still receiving the care and attention that is needed. Home monitoring systems are able to detect falls, abnormal daily patterns, and if an individual leaves the home. Outside the home, GPS systems can track an individual's location and if/when they reach their destination. The kitchen can be equipped with a refrigerator that monitors foods' freshness and when a needed item is gone and needs to be purchased. Advances in cooking technology include a microwave that evaluates the foods being prepared and consumed to ensure a balanced diet is maintained.

Caregiver robots such as Paro, Mobiserv, GiraffPlus, and CompanionAble Robotic Companion are in the very early stages of development. These robots can provide companionship, reminders of daily activities (when to eat lunch, for example), encouragement to exercise, and a link to friends and family through video chat. Robots also monitor an individual's patterns to alert the caregiver to any changes or signs of a problem.

Autonomous vehicles may open up the opportunity for care recipients to attend doctor appointments independently, without the aid of a caregiver.

With the advent of many new technologies that can assist caregivers and their loved ones, maintaining adequate security for these advances is paramount. Ensuring that the state is up to date on current trends will promote increased security of new technologies and, ultimately, the state's residents.

In-home monitoring and technology resources

- **Radar technology to detect falls**
- **GPS safety technology** provides the location of the wearer: devices can be used on the wrist, as a clip-on, or on a pendant. Some cars and smart phones have them – enabling you to speak or touch your desired destination – and see or hear turn-by-turn instructions.
- **Wireless sensors** around the house (in the bathroom, on the bed, door, or refrigerator, for example) that let caregivers know if there is activity out of the ordinary i.e. not leaving the bathroom.
- **Caregiver Robots:** http://www.nytimes.com/2014/07/20/opinion/sunday/the-future-of-robot-caregivers.html?_r=0
- **Paro Robots:** <http://www.parorobots.com/>
- **Mobiserv:** <http://www.mobiserv.info/> https://www.youtube.com/watch?annotation_id=annotation_3072285549&cc_load_policy=1&feature=iv&src_vid=nFZ9sUbbfe8&v=6DFJwnwzhPs
- **GiraffPlus:** http://www.giraffplus.eu/index.php?option=com_content&view=frontpage&Itemid=54&lang=en
- **CompanionAble:** <http://www.companionable.net/>
- **Autonomous Vehicles:** <http://delphi.com/delphi-drive>

